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Survivorship care plans: Prevalence and barriers to use

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Abstract

Survivorship care plans (SCPs) are intended to educate survivors and providers about survivors' transition from cancer treatment to follow-up care. Using a survey of 23 cancer programs in the South Atlantic United States, we (1) describe the prevalence and barriers to SCP use and (2) assess relationships between SCP use and (a) barriers and (b) cancer program characteristics. Most cancer programs (86%) reported some SCP use; however, less than a quarter of cancer programs' providers had ever used an SCP. The majority (61%) began using SCPs because of professional societies' recommendations. Key barriers to SCP use were insufficient organizational resources (75%) and systems for SCP use. We found patterns in SCP use across location, program type and professional society membership. Most cancer programs have adopted SCPs, but use remains inconsistent. Efforts to promote SCP use should address barriers, particularly in cancer programs that are susceptible to barriers to SCP use.

Keywords

Survivorship care plan; survey; prevalence; barriers

Introduction

The transition from cancer treatment to follow-up care with primary care providers (PCPs) can be difficult for the nearly 14 million cancer survivors in the United States [1]. Survivors have unique physical, psychological, social, and spiritual health needs. Optimal survivorship care includes (1) prevention and detection of new cancers; (2) surveillance for cancer spread or recurrence; (3) intervention for consequences of cancer and its treatment; and (4) coordination between specialists and primary care providers to ensure that all of the

survivor's health needs are met [2]. Optimal care may be compromised by PCPs' and oncologists' conflicting perspectives on their roles in survivorship care. Conflicting perspectives among PCPs and oncologists may result in the duplication or omission of prevention, detection, surveillance, or treatment services [3]. Survivors often feel poorly educated regarding psychological, social and sexual health issues [4] and their risk for recurrence [5], and they are often dissatisfied with care following cancer treatment [6].

To mitigate these concerns, the Institute of Medicine (IOM) recommended survivorship care plans (SCPs) as instruments to educate survivors and providers regarding the type of cancer, treatment and services received, and timing and content of recommended follow-up care [2]. Many professional societies now require cancer programs to use SCPs (i.e., develop and deliver to survivors and PCPs) [7]; however, barriers may impede cancer programs' SCP use [8].

Empirical evidence of the prevalence and barriers to SCP use is limited. Estimates of SCP use prevalence are often tangential to primary research findings, and are from a small subset of cancer programs [8, 9], a single state [10], or a very small number of cancer programs [11-13]. Existing estimates provide limited information regarding the characteristics of cancer programs that use SCPs, such as their location, annual incident cancers, program type, or membership in professional societies. Evidence of barriers to SCP use often relates to the substantial resources required for SCP use [8, 9, 12]. The extent to which SCP use is impeded by other barriers, such as lack of readiness, management support, or a positive climate for change, remains unclear.

We address these gaps in the literature by assessing the prevalence of SCP use using a survey of cancer programs with a wide range of characteristics including location, annual incident cancers, professional society memberships, and program type; assessing a wide range of barriers to SCP use, such as lack of readiness, management support, or climate for change; and assessing relationships between SCP use and (1) barriers and (2) cancer program characteristics. Understanding patterns in prevalence and barriers to SCP use may improve efforts of quality improvement organizations and professional societies to educate providers regarding the use of SCPs.

Methods

Overview

Our study sample consisted of employees with knowledge of SCP use in South Atlantic Division American Cancer Society member programs. These programs had attributes that made them an attractive study sample: The second author (DM) had a relationship with the South Atlantic Division of American Cancer Society that made the organization amenable to encouraging member programs to participate, and they represented a wide range of annual incident cancers, program types, and professional society memberships.

A team of experts in survivorship, dissemination and implementation of innovations in cancer care, and survey methodology developed the survey. It was based on a review of the IOM report [2] and scientific literature. The survey was refined based on a cognitive

interview with an employee with knowledge of survivorship care plan use in a cancer program not included in the final study sample. Survey items were phrased to elicit responses regarding SCP use any time in their cancer program's history. The final survey consisted of 12 items measuring the prevalence and barriers to SCP use (see Table 1).

In August 2011, on behalf of the first author, the South Atlantic Division of the American Cancer Society invited member cancer programs (n = 71) to participate in the study. To protect the privacy of member cancer programs, the South Atlantic Division of the American Cancer Society provided to the first author contact information only for employees with knowledge of survivorship care plan use in their cancer program who agreed to participate in the study (n = 26; 36.6% of eligible cancer programs). In September 2011, one employee from each cancer program was invited via email to respond to an online version of the survey (Qualtrics Labs, Inc.). Two weeks later, a paper version of the survey was sent via first class mail to employees who did not respond to the email invitation. The following week, a postcard was sent via first class mail to employees who received the paper version of the survey, thanking those who responded to the survey and encouraging those who had not yet responded to do so. Finally, the first author contacted non-respondents by phone, encouraging them to respond to the survey. Employees in 23 cancer programs responded to the survey, for a response rate of 88% of those contacted.

To compare the characteristics of responding cancer programs to other cancer programs the South Atlantic United States, and to assess the relationship between SCP use and cancer program characteristics, we gathered information regarding cancer programs' location, annual incident cancers, and American College of Surgeons-designated program type, and professional society membership. Cancer programs' location, annual incident cancers, and American College of Surgeons-designated program type were obtained from the American College of Surgeons website [14]. Cancer programs' membership in the following professional societies was obtained from professional societies' websites: Association of Community Cancer Centers [15]; American Hospital Association [16]; American Society for Clinical Oncology [14]; and Commission on Cancer [17]. The institutional review board at the University of North Carolina at Chapel Hill deemed the study exempt from human subjects review.

Variable descriptions

Survey items and response options are listed in Table 1. We defined an SCP as a written document that often, but not always, includes the following information regarding care after cancer treatment is complete: surveillance; preventive care; wellness behaviors; and symptoms to report. To measure *prevalence of SCP use*, we asked respondents whether or not anyone in their cancer program had ever used an SCP. Secondary measures of SCP use included the percentage of providers who used SCPs (defined as physicians, physician assistants, nurse practitioners, and nurses); the percentage of survivors for whom SCPs were used; and the percentages of survivors and PCPs to whom SCPs were delivered.

To measure *barriers to SCP use* in cancer programs in which SCPs were not used, we asked respondents why SCPs were not used. In cancer programs in which SCPs were used, we asked about factors that made it difficult to use SCPs. Respondents also had the opportunity

to provide open-ended responses regarding barriers to SCP use. To understand the impetus to use SCPs, we asked respondents why SCPs were used in their cancer programs.

Cancer programs' *location* was captured at the state level. We defined *annual incident cancers* as the cancer program's unduplicated number of cancer patients in 2011. American College of Surgeons-designated *program types* included the following: Affiliate hospital cancer program; community hospital cancer program; community hospital comprehensive cancer program; freestanding cancer center program; hospital associate cancer program; integrated cancer program; National Cancer Institute-designated comprehensive cancer program; National Cancer Institute-designated network; network cancer program; pediatric cancer program; pediatric cancer program component; teaching hospital cancer program; and Veterans Affairs cancer program. Cancer programs were considered a member of one of the following professional societies if they were listed on the member list website: Association of Community Cancer Centers [15]; American Hospital Association [16]; American Society for Clinical Oncology [14]; Commission on Cancer [17].

Analysis

To describe the prevalence and barriers to SCP use, we report response frequencies and percentages. To compare (1) respondents to other South Atlantic US cancer programs and (2) cancer programs that used SCPs to those that did not use SCPs, we used t-tests for continuous independent variables (e.g., annual incident cancers) and chi-square statistics for categorical independent variables (e.g., program type). To assess variation in the percentage of providers who used SCPs and the percentage of survivors for whom SCPs were developed, we used t-tests for binary independent variables (i.e., barriers to SCP use, professional society membership) and correlations for continuous independent variables (e.g., annual incident cancers). Relationships between variables were considered significant at the $p < .05$ level. The unit of analysis was the cancer program. Analyses were conducted using Stata 12 (Stata Corp., College Station, TX).

Results

Respondents' cancer programs had more annual incident cancers than other South Atlantic US cancer programs ($p < .001$). Respondents underrepresented community hospital cancer programs ($p = .01$) and National Cancer Institute-designated comprehensive cancer programs ($p = .03$); they overrepresented teaching hospital cancer programs ($p < .0001$). Respondents were more likely to belong to the Association of Community Cancer Centers ($p = .04$) and Commission on Cancer ($p = .02$) than other South Atlantic US cancer programs. There were no other differences between respondents and other South Atlantic US cancer programs.

Of the 23 respondents, seven were registered nurses (31.8%); six were administrators, such as service line directors (27.3%); three were nurse practitioners (13.6%); two were physicians (9.1%); two were PhDs (9.1%); and two were social workers (9.1%). Respondents reported an average of 1859 annual incident cancers (range: 1129-3248). Cancer program types included community hospital comprehensive cancer programs (52.4%), NCI-designated comprehensive cancer programs (9.5%), and teaching hospital cancer programs (38.1%). Respondents' cancer programs participated in professional

societies including the American Hospital Association (13.6%), Association of Community Cancer Centers (68.2%), and Commission on Cancer (95.5%).

Prevalence of SCP use

The majority (86%) of respondents reported that someone in their cancer program had used SCPs at least once (see Table 1). However, most respondents (76%) indicated that less than a quarter of providers in their cancer programs had ever used an SCP. All respondents indicated that SCPs were used for fewer than half of survivors. In most cancer programs, SCPs rarely reached their intended audience: Most respondents (62%) reported that SCPs were delivered to 50% or fewer of survivors for whom SCPs were developed; half (50%) of respondents reported that SCPs were delivered to 25% or fewer of survivors' PCPs.

Barriers to SCP use

Most (61%) respondents reported that cancer programs began using SCPs because of professional societies' recommendations (see Table 1). Among all respondents, the most frequently reported barriers to SCP use included: insufficient organizational resources for using SCPs, such as time, staff, money and training (75%), and the fact that some professional societies do not yet require SCP use for accreditation (62%). Among respondents who indicated an "other" barrier to SCP use, open-ended responses often referred to lack of systems to facilitate SCP use. For example, one respondent cited as a barrier to SCP use lack of "electronic [SCPs] that populate from...[electronic medical records]." Another cited lack of "systematic referral to [a] survivorship nurse."

Relationships between SCP use and (1) barriers and (2) cancer program characteristics

We found no relationship between SCP use and barriers: Barriers did not differ between cancer programs reporting no SCP use and cancer programs reporting some SCP use. We found no relationship between barriers to SCP use and the percentage of providers using SCPs or the percentage of survivors to whom SCPs were delivered.

Cancer programs reporting no SCP use and cancer programs reporting some SCP use differed only with regard to location: Cancer programs reporting no SCP use were located in a single state ($p=.001$). Although differences from cancer programs reporting some SCP use were not statistically significant, cancer programs reporting no SCP use were all teaching hospitals, and none was a member of the American Hospital Association. We found no relationship between cancer program characteristics and the percentage of providers using SCPs or the percentage of survivors to whom SCPs were delivered.

Discussion

This study's objective was to describe the prevalence and barriers to the use of SCPs, an instrument intended to educate survivors and patients regarding survivors' transition from cancer treatment to follow-up care, and to assess relationships between SCP use and (1) barriers and (2) cancer program characteristics. Results indicate that most cancer programs have adopted SCPs, but in most cancer programs less than a quarter of providers have ever

used an SCP. This is consistent with previous estimates of SCP use, which range from 14 to 43 percent [9-11].

Also consistent with previous studies, we found that when SCPs are developed, they are often not delivered to survivors or PCPs [10, 18]. There are several possible explanations for this finding. First, respondents may not have known how frequently SCPs were delivered to survivors or PCPs. This explanation is unlikely, however, because no respondent selected the “Don’t know” response option (Table 1). And if respondents were reluctant to admit not knowing how frequently SCPs were delivered to survivors or PCPs, social desirability bias would likely have inflated estimates; our low estimates of SCP delivery suggest that this was not the case. Second, our findings reflect a single point in time, relatively soon after professional societies began to require SCP use. At the time of our survey, respondents’ cancer programs may not have implemented plans to deliver SCPs. A survey at a later date might have found more widespread SCP delivery.

Third, cancer programs may develop SCPs to meet minimum standards for compliance with professional societies’ SCP use requirements. Cancer programs using SCPs for the sole purpose of complying with professional societies’ requirements may be disinclined to make the organizational changes required to deliver SCPs to survivors and PCPs. Indeed, our results suggest that professional societies’ requirements compel cancer programs to use SCPs; insufficient organizational resources and systems are barriers to SCP use. These results are consistent with other studies of barriers to SCP use. Dulko and colleagues (2012) found that a substantial barrier to SCP use was the time necessary to obtain the information required to create an SCP [12]. Chubak and colleagues (2012) found that lack of staff impeded SCP use. Others have cited as barriers lack of templates, time to complete SCP, training and reimbursement for SCP use [10, 11, 19, 20].

Patterns in SCP use suggest that some cancer programs may be more susceptible to barriers to SCP use. Each of the cancer programs reporting no SCP use was a teaching hospital. Teaching hospitals may have fewer resources available to commit to using SCPs than other cancer program types [21]. None of these programs was a member of the American Hospital Association. As such, they did not participate in the American Hospital Association’s initiatives to improve hospital quality and organizational performance; these initiatives may have promoted SCP use [22].

Our study has several limitations. First, survey items were not validated. This measurement bias emphasizes the need for the development of measures in dissemination and implementation research [23]. Validated measures will promote strong research in a rapidly developing field. Second, social desirability bias may have caused respondents to over-report SCP use. Third, the majority of respondents were registered nurses and administrators. Their perspectives on SCP use may differ from the perspectives of other cancer program employees, such as medical directors, physicians, and other providers. Fourth, our sample size limited our ability to draw conclusions regarding relationships between SCP use and (1) barriers and (2) cancer program characteristics. Future studies should use larger samples. Fifth, our study results have limited generalizability. Respondents who agreed to participate in the study may have been more likely to respond if their cancer

programs used SCPs. Further, responding cancer programs were not representative of other South Atlantic US cancer programs in terms of annual incident cancers, some program types, and membership in some professional societies; ostensibly, responding cancer programs were not representative of US cancer programs. Future studies should use a nationally representative sample of cancer programs.

Despite these limitations, our findings have implications for educating survivors and providers about survivors' transition from cancer treatment to follow-up care. Professional societies' efforts to educate providers regarding the use of SCPs may have a stronger influence when complemented by efforts to address barriers to SCP use. For example, professional societies may consider publicizing methods of SCP use that minimize the burden on organizational resources and maximize the use of organizational systems to facilitate SCP use. In particular, these efforts should target cancer programs that are susceptible to barriers to SCP use, such as those in under-resourced teaching hospitals.

Additional research is needed to better understand patterns of SCP use across professional societies, SCP templates (e.g., Journey Forward), and tumor groups. For example, if SCPs have been used most widely with breast cancer survivors, efforts to educate providers regarding SCP use may be most successful if they are focused on breast cancer care providers. Before this research is conducted, however, several methodological concerns must be addressed. First, the definition of "SCP" must be clarified. Currently, several, often conflicting, definitions exist. Second, reliable and valid measures of SCP use and its determinants must be developed. For example, is including SCPs in health records sufficient to educate survivors and providers regarding survivors' transition from cancer treatment to follow-up care, or must SCPs be delivered to survivors during a clinical visit and sent to providers to qualify as effective SCP use? Third, optimal survey respondents should be identified. Do medical directors have intimate enough knowledge of SCP use, or are perhaps nurse managers more appropriate respondents? Addressing these methodological concerns will bring us closer to understanding patterns of SCP use; understanding patterns of SCP use will help to target efforts to educate providers regarding SCP use and, in turn, the potential for survivors to benefit from SCPs as intended.

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Table 1
Survey item response options and frequencies (n = 23)

#	Item	Response options	Frequency (%)
1	Has anyone, including you, in your cancer program <u>ever</u> used an SCP?	Yes	86
		No	14
		Don't know	0
2	Approximately what percentage of providers in your cancer program has <u>ever</u> used an SCP?	0-25%	76
		26-50%	18
		51-75%	0
		76-100%	6
		Don't know	0
3	For approximately what percentage of all survivors in your cancer program are SCPs used?	0%	0
		10%	42
		20%	17
		30%	17
		40%	17
		50%	8
		>50%	0
		Don't know	0
4	For approximately what percentage of these survivors for whom SCPs are used are SCPs delivered to the <u>survivor</u> ?	0-25%	31
		26-50%	31
		51-75%	0
		76-100%	38
		Don't know	0
5	Approximately what percentage of SCPs is delivered to the survivors' <u>primary care providers</u> ?	0-25%	50
		26-50%	0
		51-75%	0
		76-100%	50
		Don't know	0
6	Why did providers in your cancer program begin using SCPs? (Check all that apply.)	American College of Surgeons (ACS) guidelines	61
		American Society for Clinical Oncology (ASCO) guidelines	61
		Institute of Medicine's (IOM) <i>From Cancer Patient to Cancer Survivor</i>	56
		National Comprehensive Cancer Network (NCCN) evidence	44
		Other _____	44
		Association of Community Cancer Center (ACCC) guidelines	22
		Advice from colleague	17
		National Coalition for Cancer Survivorship (NCCS)/Lance Armstrong Foundation guidelines	17
7	In your opinion, why don't providers (physicians, physician	Other _____	67
		The cancer program is not ready to make the changes necessary	33

#	Item	Response options	Frequency (%)
	assistants, nurse practitioners, nurses) in your cancer program use SCPs? (Check all that apply.) ^a	to use survivorship care plans.	
		Using SCPs is not expected.	33
		Providers do not know about SCPs.	33
		Providers do not know enough about SCPs to use them.	33
		No one champions using SCPs.	33
		Resources aren't sufficient to use SCPs (e.g., time, staff, money, training).	33
		Middle managers (e.g., department supervisor, nurse manager) don't support using SCPs.	0
		Using SCPs is not rewarded.	0
		Using SCPs is not supported.	0
		Providers don't feel that SCPs are an effective tool for easing the transition from treatment to survivorship care.	0
		Top managers (i.e., CEO, CFO, COO, Medical Director) don't support using SCPs.	0
8	In your opinion, when providers have been able to use SCPs, which of the following have made it <u>harder</u> to use SCPs in your cancer program?	Resources aren't sufficient to use SCPs (e.g., time, staff, money, training).	76
		Using SCPs is not rewarded.	29
		No one champions using SCPs.	29
		Providers don't feel that SCPs are an effective tool for easing the transition from treatment to survivorship care.	12
		The cancer program is not ready to make the changes necessary to use survivorship care plans.	12
		Other _____	3
		Using SCPs is not expected.	5
		Middle managers (e.g., department supervisor, nurse manager) don't support using SCPs.	0
		Using SCPs is not supported.	0
		Top managers (i.e., CEO, CFO, COO, Medical Director) don't support using SCPs.	0

^aFor those who responded "no" to item 1.